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RESEARCH BRIEFING NO. 3

Interviews with people at the end of life: End of Life Care for People with Alcohol and Drug Problems

“You were never believed and you were always made to feel like rubbish and it takes a lot to get past that and then start maybe putting a bit more trust in these people again.”
(Richard)

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Key findings

1. People with substance problems often anticipate discrimination from health and social care staff, feeling a level of mistrust that can contribute to their late presentation to healthcare services.
2. Many people with substance problems feel regret, guilt and shame around their substance use and may have fractured relationships with friends and family as a result. Both of these issues may impact upon the quality of their end of life and their experience of care.
3. Like many among the general population, people with substance problems may not be fully informed about their end of life condition. Finding ways for health practitioners to introduce such conversations, early in their care, would avoid unnecessary distress for both PWEs¹ and their families².
4. Past experiences of discrimination from health services may leave people with substance problems mistrustful and with limited psychological resources to engage with health and social care.
5. Stigmatising attitudes still shape the way that many healthcare providers understand and respond to people with substance problems: a situation which is exacerbated by a fragmented and under resourced health care system.
6. Empathetic health professionals could help people with substance problems by adopting a more holistic biopsychosocial approach to their care, including space for conversation around how they may be adjusting to end of life care.
7. Taking a holistic approach to ensuring a good quality of life allows 'the whole person' to be cared for, rather than focusing specifically on one stigmatised aspect of their lives and leaves individuals less vulnerable to negative health practitioner attitudes regarding their past substance use.
8. Hospices can offer a more caring environment for people with substance problems to accept their end of life situation and attend to their fundamental care needs.

¹ Person With Experience (of both substance use problems and end of life care needs).

² Families, friends and carers.

Background

The needs of people with substance³ problems rarely feature within health and social care policy. Despite recognition of the need to address complex multiple morbidities for the UK population, there is a lack of research about palliative and end of life care for people with substance problems, and a lack of policy and practice attention to their specific experiences and needs. In particular, the 'recovery' focus of Government substance use policy is inappropriate for people needing end of life care. It fails to address the needs of people who cannot meet requirements for regular service attendance or who will not recover.

Thus, there is a clear UK policy vacuum wherein substance use policy does not account for the needs of people approaching the end of life, and palliative care policy overlooks people with unpredictable life-shortening conditions. This is accompanied by substantial limitations in service provision, with the demands of substance use treatment inadvertently excluding people with deteriorating physical health, and palliative care pathways remaining heavily focused on cancer care.

It is also important to note that many people have problems with substances but never engage in treatment. Therefore, as they approach the end of their life, services may be completely unaware of their substantial care needs. However, the current policy aim of reducing inequalities in access to palliative and EOL care provides an opportunity to develop new pathways and approaches to care that could substantially improve the situation for people using substances as they approach the end of life and for those who care for them.

This Briefing summarises findings from the PWE strand of a wider research programme exploring end of life care for people with problematic substance use.

Methodology

The aims of this research were to:

1. Document how substance use and end of life services have supported people with substance problems and chronic or terminal illness.
2. Report the good practice and challenges that people faced in accessing support services.
3. Provide an opportunity for people reaching the end of their lives to comment on the care and support they received and how that may be improved.

³ Alcohol and other drugs.

This strand of the research comprised in-depth, semi-structured, qualitative interviews with 11 people approaching the end of their life who had (current or past) substance use difficulties. Interviewees were recruited from a range of sources, including hospices, substance use treatment services and community networks.

All interviews were audio recorded and fully transcribed. The data were analysed using thematic analysis (Braun and Clarke, 2006⁴).

Findings

The 11 people who participated in our research were almost evenly split between having alcohol or illicit drug difficulties. On average they were approaching the end of their lives 25 years earlier than is expected of the general UK population. Liver failure was the most common life-shortening condition reported, with COPD and lung cancer being the next most reported health problems.

At the time of interview, six participants were not in touch with substance use services, one of whom had never had any contact. Among the five participants who were accessing substance use services, three were receiving a methadone prescription and the two people with alcohol problems were continuing to get support from their local service despite being abstinent for over a year. Three participants had not used substances for over eight years (for two people that was alcohol, and for the other drugs). Four of the participants were accessed through a hospice, four were accessed through community links and three were accessed through substance use services.

In furthering our understanding of end of life care for people with substance problems, our thematic analysis identified five broad themes outlined in figure 1 below:

⁴ Braun V and Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*. 3, 77-101.

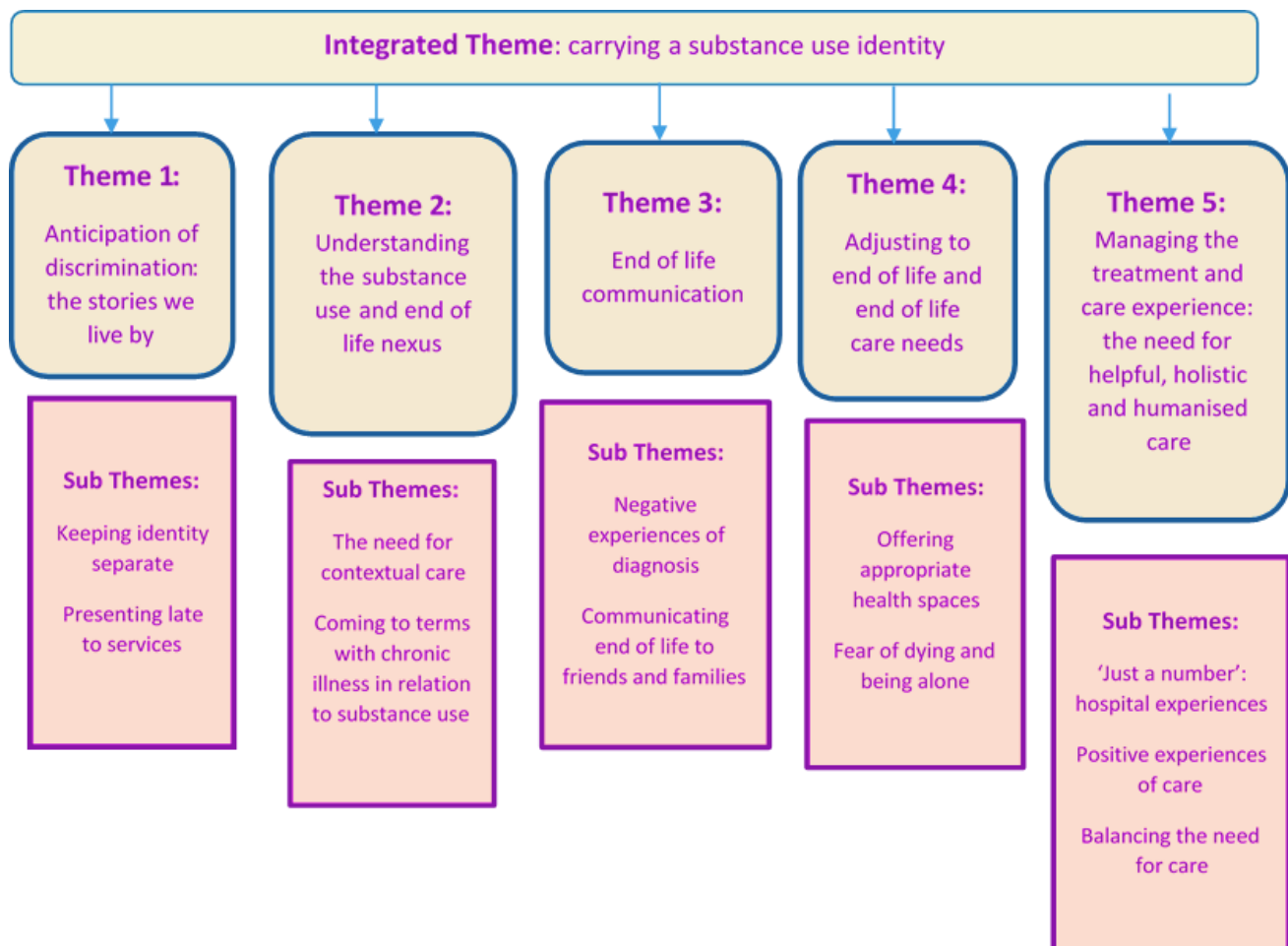


Figure 1: Main analytical sub-themes and integrated theme

Anticipation of discrimination

Many of the people we interviewed anticipated discrimination from health and social care staff, feeling a level of mistrust that resulted in their late presentation to services.

You were never believed and you were always made to feel like rubbish and it takes a lot to get past that and then start maybe putting a bit more trust in these people again ... We've been treated so badly in the past ... [Pharmacy], just being told to wait outside in the rain, so they dealt with a 'normal' person ... then get called in ... someone else might come in, you're told to wait.' (Richard)

Some of those who did access health and social care services kept their substance use secret as one way of trying to minimise discrimination.

It [drug use] could only be detrimental for me to bring it up or make other people aware of it - especially other patients. It could only be detrimental in my opinion because everybody isn't

all: "Good on you, you're a recovering addict, stay strong."
You're going to get people who are going: "Smack-heads!
Where's my phone? The smack-head's took it." (Rob)

Others tried to continue caring for themselves at home with little or no formal support, accessing emergency services when an acute health crisis made that necessary.

It were just before Christmas, I got took into hospital, I'd gone bright yellow. I'd been drinking, I was in that much pain. I didn't know it was actually coming from my liver and I was taking a load of morphine and stuff for the pain. I sort of OD'd myself a bit on all the painkillers, not realising what I was doing because I was drinking as well. (Steven)

Understanding substance use and end of life care nexus

As well as dealing with complex health problems and the need to adjust psychologically to end of life, people with substance problems are likely to feel deep regret, guilt and shame around their past behaviour. It is important to create safe spaces where such feelings can be acknowledged, to minimise their impact upon the end of life and experience of care.

[The gastroenterologist] He's treated me as another person who just drank, he didn't know my background, he didn't know I was abused mentally and physically by my husband ... I was beaten, he didn't know that, he just thought a six stone alcoholic and that is all he could see because he had no delving into my past. (Barbara)

Rather than framing substance use dependency as a 'choice' and a self-inflicted behaviour that warrants little sympathy, through seeking background contextual information from each person, health and social care practitioners can gain a different insight that enable better relationships to form around trust, care and compassion.

I wish now I had time enough to help someone else through it ...
But I just wish I wasn't like this [dying], I'm only 38. (Steven)

End of life communication

The majority of participants had not been properly informed about their end of life condition. Susan queried her doctor when she saw her chest X-ray, while Rob had no idea why a hospice was being suggested:

I happened to look at the screen and I saw for my own eyes, just how bad it was in my lungs. ... and I mentioned it to the doctor, ... I said: "I suppose I'd better start telling my family how bad it is because I've seen it for myself now." And he said, "Yeah." And that made me think, was he ever going to tell me or not? (Susan)

The nurse explained, she said "You know you're very ill?" And I've flippantly remarked, "No shit, ... my heart is working at 14%, I know I'm ill." She went, "No you're really ill." She went, "You could have as little as a year to three years to live." ... It came across as almost flippantly mentioned, but I think it was more a case of I think she presumed that I already knew. (Rob)

So, particularly for people not in regular contact with healthcare services, there is a need to look at ways in which early conversations can take place in order to avoid unnecessary distress for the patient and their relatives. Having to communicate their prognosis to friends and family was an additional burden for many of the research participants that could be better supported.

Adjusting to end of life and end of life care needs

For everyone, dying elicits a range of difficult emotions; not least fear of the dying process, of dying alone or dying in pain.

I know I'm going to go through some more pain, the pain's going to get worse and I know that for a fact and I might not even be able to speak. I can be just like a zombie or just out of it, getting drugged up and then pass away. That's the most thing that I'm afraid of. (Steven)

For people with substance problems, adjusting to end of life and accepting the need to receive formal healthcare meant having to balance a stigmatised substance using 'outsider identity' with a dependent 'insider identity' of needing care. Rob spoke of feeling "a bit stage-fright-ish" as the younger "new guy" in the hospice. This can generate feelings of frustration and anxiety over a lack of control, particularly for younger people, that can impede the provision or receipt of optimal care.

It must have been a good six months before I was accepting of being in somewhere like this. And a couple of the nurses, they weren't nice to me ... I've met some lovely people here, you know, elderly people. ... But what those nurses fail to remember is that I am 58 not 98. (Nicola)

Past experiences of discrimination from health services may have left individuals quite mistrustful and with limited psychological resources to engage with therapeutic discussions. Empathetic health professionals could help people with substance use problems by encouraging them to talk about their feelings and experiences as a means of facilitating smoother adjustments towards hospice and other care provision. This is important for people with substance problems who are adjusting to end of life, as many have experienced, loneliness and isolation due to stigma and shame and, therefore, may fear 'opening up' to health professions about their thoughts and feelings.

Managing the treatment and care experience: the need for helpful, holistic and humanised care

Experiences of end of life care vary, depending on the psychological, physical, social and spiritual needs of the person and how those relate to their health condition. Stigmatising attitudes still shape the way that many healthcare providers understand and respond to people with substance problems. This is exacerbated within a fragmented and under resourced health system where the 'snap shot' consultation or hospital encounter are devoid of knowledge about the person's social context and therefore each person is treated as a 'case' rather than an individual with a unique history.

When I'm in hospital, it's just as though I'm a number. Do you know what I mean? ... I need help. (Peter)

Hospice experiences were positive, however, offering a caring environment for individuals to accept their situation and attend to their fundamental support needs. The focus on holistic care within hospices enables each person to be ascribed a 'whole' integrated identity which does not focus specifically on one stigmatised aspect of their lives, but rather, attends to what can make their life better and more comfortable in the 'here and now.' This makes individuals much less vulnerable to stigmatising attitudes regarding past substance use.

'I think it's absolutely brilliant, absolutely fantastic. I can ask the nurses anything and if they talk about certain terms, I just say, "Can you say that in black and white?" They tell me everything and it's all right, it is.' (Gill)

Contrary to what health practitioners may expect (about people with substance problems being 'demanding' or 'manipulative'), they actually often minimise their needs and rather than seeking opioid painkillers to 'misuse', many ex-drug users may actually need encouragement to take the drugs they need:

For quite some time [I] resisted using any pain killers because of the association, and I was able to put up with a lot of pain which was ... it was a real battle ... that was a tough time ... and [wife]

said “Look come on, you’re in a lot of pain. You’re not a junkie anymore ...” But it was a big battle that went on in my head, it was a real, it was a difficult thing, and I still feel guilty at times, and it’s very, it’s still difficult, it’s really weird.’ (Richard)

Therefore, understanding some of the relational issues that surround substance use and identity may help to avoid misunderstandings around care provision. For example, avoiding the ‘junkie’ stereotype and associated behaviours enables a move towards an individualised approach to optimal care.

Summary

For people with substance use problems, receiving an end of life diagnosis may be particularly difficult to cope with because:

- Health professionals may not communicate well about their health condition – in part because of their stigmatising attitudes towards substance use but also due to the unpredictable nature of many end of life trajectories for people with substance problems;
- People with substance problems may struggle to understand the end of life message because: (1) they are anticipating discrimination from the healthcare provider and shutting down emotionally to try to protect themselves from judgemental sources of authority; (2) they may be experiencing memory or cognitive capacity problems; (3) they may have few family members or carers around them to help them absorb the information; and (4) they are likely to have presented to healthcare services late, and may therefore be very close to death and need to make decisions/plans quite rapidly.
- Current provision of emotional support may be insufficient for people with problematic substance use who may be used to being secretive over their health and are not used to having to depend upon health practitioners to help them. Thus, there is a need to build trust between PWEs and healthcare professionals to help PWEs overcome feeling marginalised and stigmatised by the health ‘system’.

This research – into both end of life **and** substance use care for people with life-shortening conditions – did not uncover much information about end of life care within substance use settings. This warrants further examination because it may suggest that as people with substance problems become increasingly ill, they tend to leave or be discharged from treatment services which are largely unaware of the severity of their health condition(s). Our data also suggest that some people who have struggled with substance use may need prolonged support from treatment services even after achieving abstinence.

Conclusion

This research provides unique insight into the end of life experiences of people with alcohol and other drug problems. Much can be done to better meet their support needs, and this is of considerable importance given the growing number of people who are likely to approach the end of their life with a current or past substance problem.

Implications for practice

- Raising health and social care practitioner awareness of having a 'substance using identity' is important to the provision of effective end of life care.
- Talking about end of life and receiving a clear diagnosis (even if the prognosis is uncertain) is important for people with problematic substance use.
- Helping people overcome feelings of guilt or self-blame about 'bringing their premature death on themselves' is important to empathetic care. This may be especially important if family or other support networks have broken down.
- Hospital and medical treatment experiences were described as considerably worse than hospice care due to the absence of humanistic care. Considering the provisions of more appropriate health care environments may help to combat loneliness and enhance belonging for people with both substance use problems and life-limiting conditions.

Implications for policy

- Health and social care practitioners *still* need training in more compassionate approaches to working with people who have substance use problems and more proactive ways of engaging people into substance use treatment.
- Greater attention needs to be paid to identifying those with multiple complex health needs who may die prematurely, to enable them to access palliative care services, particularly the role that substance treatment agencies could play. This entails better identification of those who are approaching the end of life from conditions other than cancer and more effective joined-up working between treatment agencies and palliative care services.
- A more holistic approach to support for people with multiple complex health and social care needs is also required to overcome the current problematic and ineffective single-issue treatment pathways.
- Ways in which better and more effective lines of communication need to be considered regarding end of life diagnosis and prognosis.
- Introducing greater flexibility in support and treatment is required: time, space and place all require re-thinking in health and social care provision to enhance the adaptability and availability of services. More consideration needs to be given to diverse, appropriate and aligned health spaces (for

example, age / gender specific environments that enable better engagement).

- The potential role that communities could play – not least in reaching out to individuals who are reluctant to engage with formal healthcare services - warrants particular attention.
- Support and guidance to help with the difficulties of communicating end of life to families (including children), friends and carers is also needed.

Implications for research

Further research recommendations would be to:

- explore more comprehensively some of the main barriers to effective end of life communication,
- explore how best to engage substance use services in end of life care work,
- work with people with experience of problematic substance use and life-limiting conditions in developing an effective model of care.

Further Information

- Our programme of research on *End of Life Care for People with Alcohol and Other Drug Problems* has six strands. This Briefing summarises Strand 3, which aimed to investigate the experiences of people with end of life care needs and (current or past) substance problems.
- This Briefing was authored by Sam Wright, Jo Ashby and Sarah Galvani (Manchester Metropolitan University).
- We thank the Big Lottery Fund for funding the wider project of which this Briefing is a part. We also thank all the interviewees who gave their time so generously to speak with us, and our colleagues who helped with recruitment.
- Ethical approval for Strand 3 was obtained from Manchester Metropolitan University, and all interviewees gave informed consent.
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